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# 1 Title

- 2 Understandings of Cervical Screening in Sexual Minority Women: A Q-Methodological Study
- 3

## 4 Abstract

5 Discursive perspectives argue that cervical screening carries social and moral meaning. Overlooked 6 by research into the health needs of sexual minority women, previous literature that has examined 7 uptake of cervical screening has instead targeted increasing attendance via information and service 8 provision. In order to explore the diversity of meanings that British sexual minority women have 9 about cervical screening, the Q-sorts of 34 sexual minority women were factor analysed by-person 10 and rotated to simple structure using Varimax. The five factors are interpreted and discussed relative 11 to competing discourses on information provision within cervical screening. The five accounts are 12 labelled 'cervical screening is': an essential health check that women have the right to refuse; a 13 woman's health entitlement; a vital test but degrading experience; a sensible thing to do; and an 14 unnecessary imposition for some women. Critical approaches to informed choice are explored with attention to recent developments in cervical cancer prevention. Findings highlighting the need for 15 16 affirmation of diversity within healthcare are considered in relation to existing criteria for UK national 17 screening programmes. 18 19 Key words 20 cervical screening, informed choice, Q-methodology, sexuality, social constructionism 21 22 **Author Details** 23 Zoë Darwin completed this research during her MSc in Health Psychology at the University of 24 Teesside, UK. She is particularly interested in women's health and is currently undertaking a PhD at 25 the University of Manchester, UK. 26 Address: Maternal and Fetal Health Research Group, Faculty of Medical and Human Sciences, 27 University of Manchester, St Mary's Hospital, Hathersage Road, Manchester, M13 0JH, UK. 28 Email: zoe.darwin@postgrad.manchester.ac.uk 29 30 Carol Campbell is a Chartered Health Psychologist and Associate Professor at Zayed University, 31 Dubai, United Arab Emirates. Prior to this appointment she worked for 10 years at the University of 32 Teesside teaching at both undergraduate and postgraduate levels. Her applied research focuses 33 predominantly on lay perceptions and causal attributions of adult health and illness. 34 Address: Department of Natural Science and Public Health, College of Arts and Sciences, Zayed 35 University, Dubai Campus, PO Box 19282, United Arab Emirates.

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### 38 Introduction

39 An example of secondary prevention, cervical screening aims to detect and monitor pre-cancerous 40 cells at an asymptomatic stage in order to provide treatment where necessary, thereby preventing 41 cancer developing. Guidelines vary internationally, with most industrialized countries recommending 42 screening between every one and five years within a target age range (approximately 20 to 69 years). 43 Unlike many countries where cervical screening comprises part of women's routine health 44 examinations, the UK has a national cervical screening programme (NHSCSP), delivered in the 45 context of the National Health Service (NHS). Established in 1988, the NHSCSP followed demands 46 for wider access to screening, partly by feminist and women's health activists. Current NHSCSP 47 guidelines based on effectiveness and cost-effectiveness data 'call and recall' women every three to 48 five years between the ages of 25 and 64, unless commencing earlier via opportunistic screening 49 (Department of Health (DOH), 2007). Prior to 2003 when the guidelines were amended, the lower age 50 parameter was 20 years of age. The programme's estimated success relies upon uptake by 80 percent 51 of the population, reflected by its introduction alongside general practitioner contracts whereby the 52 government offers target-based financial incentives to deliver screening within primary care (DOH, 53 1989). Consequently, research has targeted increasing 'attendance', primarily by investigating uptake 54 differences associated with age, socioeconomic status and ethnicity (e.g. Orbell and Sheeran, 1993).

55

Sexual minority women (SMW)<sup>1</sup> have traditionally been overlooked in this area (Farquhar et al., 56 57 2001). Invisibility is likely further attributable to the role of sexual risk factors in the aetiology of 58 cervical cancer, where 'sexual activity' is presented as synonymous with 'heterosexual activity' and, 59 moreover, tantamount to coitus (for further discussion of the 'coital imperative', see McPhillips et al., 60 2001). However some SMW, including those that self-identify as 'lesbian', will have been or continue 61 to be heterosexually active (e.g. Rankow and Tessaro, 1998). Moreover, sexual activity is simply the 62 distal risk factor; Human Papilloma Virus (HPV) infection constitutes the necessary, but insufficient, 63 cause of cervical cancer (Trottier and Franco, 2006). Crucially, HPV infection can be passed directly 64 between women as transmission occurs via genital skin-to-skin contact, rather than bodily fluids 65 (Franco and Harper, 2005), thus explaining HPV presence regardless of history of heterosexual 66 intercourse (Marrazzo et al., 2000).

67

Reported comparable abnormal smear rates for sexual minority and heterosexual women (Bailey et
al., 2000) in the UK has raised concern about lesbian women's risk around cervical cancer; however,
these authors compared data from lesbian sexual health clinics with national data, rather than other
sexual health clinics. Comparable rates of abnormal smears have been linked to less frequent
attendance in SMW (Matthews et al., 2004), yet such studies often fail to control for potentially

73 confounding factors that may facilitate opportunistic screening (e.g. antenatal care and oral

74 contraceptive prescription) for 'straight' women.

76 Although it is not clear that SMW are as *at risk* as straight women, apparent lowered attendance has 77 been attributed to risk perceptions, with some SMW self-reporting perceiving heterosexual women to 78 be at greater risk of cervical cancer, perhaps reflecting advice from health professionals and screening 79 guidelines (Fish and Anthony, 2005). Women-centred approaches to improve information and service 80 provision have highlighted the impact on health-seeking behaviours of experience of healthcare, 81 attitudes of health professionals, ability to disclose sexuality and heterosexism within society and the 82 healthcare system (Fish and Anthony, 2005; McNair, 2003). Consequently, recognition of SMW in 83 the NHSCSP guidelines has been demanded (Bailey et al., 2000) but remains unacknowledged (DOH, 84

85

2007; NHS, 2008).

86 Such women-centred approaches arguably tackle social exclusion and health inequalities, consistent 87 with positioning by some feminist and women's health activists of cervical screening as a right for all 88 women and source of empowerment for greater insight and control regarding women's own bodies 89 and health (Bush, 2000; Howson, 2001). However, other commentators have insisted that feminists engage with science to question whether cervical screening, particularly via a national programme, is 90 91 genuinely beneficial; both in epidemiological and psychosocial terms (Oakley, 1998).

92

93 Alternative feminist challenges originate from discursive proponents demanding attention to the social 94 and moral meanings of cervical screening, alongside possible ulterior motives behind the NHSCSP 95 (Foster, 1995, cited in Bush, 2000; Howson, 1999). Discourse analysis of medical literature, focus 96 groups and semistructured interviews with women has alternatively positioned cervical screening as a 97 form of social control, surveillance and regulation of female sexuality, carrying social obligation to 98 comply (Bush, 2000; Howson, 1999; McKie, 1995). However, such meanings have not been explored 99 in SMW, with studies either omitting any comment on sexual identity (Bush, 2000), or being limited 100 to participants presenting a public statement of heterosexuality (Howson, 1999; McKie, 1995). This 101 highlights research challenges where inherent heterosexism and risk of homophobic social 102 stigmatization increases the chance of heterosexual misclassification (Brogan et al., 2001; McNair, 103 2003). 104

105 Attention to wider meanings of cervical screening may also inform criteria that all national screening 106 programmes must meet. The criteria against which the NHSCSP was judged at its introduction 107 specified that the test be 'acceptable to the population' (Wilson and Jungner, 1968: 27), yet this 108 appears to be neglected, with the emphasis instead on biomedical procedures and cost-effectiveness. 109 Since having been updated, the criteria now specify that 'there should be evidence that the complete 110 programme (test, diagnostic procedures, treatment/ intervention) is clinically, socially, and ethically

111 acceptable to health professionals and the public' (Gray, 2004: 293). However these expanded criteria

- 112 have not translated into a fruitful research agenda that aims to examine existing programmes. To
- 113 tackle these research gaps, the current study uses Q-methodology to address the research question:
- 114 what alternative standpoints do SMW adopt towards cervical screening?
- 115

116 Q-methodology enables these research gaps to be tackled through exploring and describing the 117 diverse population of meanings and understandings that SMW have about cervical screening, rather 118 than treating SMW as a homogenous group, defined only by their sexuality. The methodology is ideal 119 for feminist inquiry, and where a particular discourse has previously dominated, given its social 120 constructionist ontology, based on the premise that people construct alternative accounts, embedded 121 in sociocultural and historicopolitical context (Kitzinger, 1987; Stainton Rogers, 1991, 1995). Q-122 methodology further fits with the epistemological aim to explore variability, rather than reduce it. In 123 practical terms, the approach is compatible with small sample sizes, advantageous for sexual minor-124 ity research due to inherent recruitment challenges (Kitzinger, 1999; Lee and Crawford, 2007) and 125 also for the resources available to this study as a master's project. 126 127 128 Method 129 130 Q-Methodology 131 Q-methodology requires participants (referred to as the P-set, equivalent to the variables) to 132 physically sort a series of items (referred to as the Q-set, equivalent to the sample). Unlike traditional 133 attitudinal research, items are assigned meaning through the contextuality of a participant's response 134 pattern (McKeown and Thomas, 1988), uncovering subjective viewpoints and understandings not 135 clearly characterized as predefined attitudes. An intercorrelation matrix of the resulting 'Q-sorts' is 136 subjected to by-person factor analysis to generate a factor structure that is qualitatively interpreted, 137 providing accounts of understandings of the social object of interest. 138

139 *Q-Set* (*The Item Sample*)

140 The Q-set was derived through sampling what is 'sayable' about cervical screening. This cultural 141 analysis was limited to literary sources (including academic journals, media and health promotion 142 texts), informal conversation and quasi-naturalistic items adapted from interview transcripts reported

- 143 in studies external to this research; this strategy is synonymous with other Q-methodological research
- 144 (see Snelling, 1999). Rather than being theory-driven, statement generation encompassed all
- 145 identified aspects (e.g. risk factors, reasons for attendance, barriers to screening, patient-professional
- 146 interactions, experience of the procedure, experience of waiting for results, the call-recall system,
- 147 discursive perspectives), provided that statements remained accessible to all participants by being
- 148 jargonfree.

- 149
- Following standard procedures (see Stainton Rogers, 1995), the initial statement selection was
  reduced to a Q-set comprising 63 items (see Table 3 later). A pilot study (n = 5) allowed statements to
  be checked for clarity, appropriate terminology and ability to discriminate between participants,
  leading to revision of 19 items. The majority concerned clarification of referents (e.g. item 11 was
  piloted as, 'People who are close to me would want me to go'), which also had the effect of the
  revised items being less informal. Five items were revised from absolute positions ('only/not
- 156 important if ...') to less extreme positions ('less/ more important if ...') in order to discriminate
- 157 between participants. The pilot study also led to minor revisions of the instructions to improve clarity.
- 158

## 159 Participants (P-Set)

160 The sampling focus is the Q-set. While attempts should be made to facilitate diversity of accounts, 161 participants need not comprise a random group, instead aiming to describe a population of ideas rather 162 than people (Stainton Rogers, 1995). Following ethical approval by the host university research ethics 163 committee, research packs were posted to 76 prospective participants approached via personal 164 contacts, local community groups (either by email advertisement or visiting in person, according to 165 the groups' preferences) and a snowballing technique. Completed packs were returned from 39 166 participants by the deadline, of which 34 were analysable,<sup>2</sup> providing an adequate number to attain 167 stability in the resulting factor structure ( $n \ge 30$ ; Brown, 1980). This response rate 29.6 percent has 168 been reported elsewhere as common given that participation is time intensive (in excess of an hour; 169 Aldrich and Eccleston, 2000).

170

# 171 Procedure

172 Data collection was achieved by independent completion of the Q-sort, and delivered via the post. 173 This process of completing the Q-sort has been undertaken in other studies (e.g. Eccleston et al., 174 1997) and does not appear to be limited as a result of the absence of the researcher. Prospective 175 participants received research packs including information concerning the nature and purpose of the 176 study, informed consent, debriefing and study withdrawal, detailed instructions, and data collection 177 materials. Informed consent was asked of participants via the return of a signed informed consent 178 form with the completed Q-sorts. Participants were then asked to sort the Q-set statements, which 179 were randomly numbered and printed onto separate labels, into piles of most disagree, neutral and 180 most agree. Participants then sorted the statements onto the response grid, configured with a 13-point 181 quasi-normal distribution (see Table 1). This was appropriate because the Q-set exceeded 60 items 182 (Brown, 1980). Once satisfied with the positions, participants affixed the adhesive labels, securing the 183 Q-sort. Finally, participants completed the comments booklet (Eccleston et al., 1997), recording 184 information concerning sorting choices and reactions to the statements alongside a duplicate of the Q-185 set, before completing the participant background information form. Participants also completed a

186	brief questionnaire on background characteristics concerning: sexual identity, sexual behaviour
187	(current and previous, with women, men, both, neither), age, and screening history (number of
188	screens, if any; age first screen; ever abnormal/inconclusive result; ever treatment required).
189	Participants were also asked to comment on their own (perceived) risk of cervical cancer; and factors
190	affecting risk. Cervical screening history did not form part of the inclusion criteria, which were
191	limited to current UK residence and self-identification as a sexual minority woman.
192	
193	
194	[Table 1 around here]
195	
196	
197	Findings
198	
199	Descriptive Data
200	The 34 participants offered the following terms in self-labelling their sexual identity: lesbian ( $n = 26$ ),
201	bisexual $(n = 9)$ , queer $(n = 3)$ , dyke $(n = 2)$ , gay $(n = 2)$ , fluid $(n = 1)$ , open $(n = 1)$ , an individual $(n = 1)$
202	1), 'I'm just me' $(n = 1)$ , '80% gay/20% straight' $(n = 1)$ . Current sexual behaviour (with women $(n = 1)$ )
203	29), men $(n = 2)$ , both $(n = 1)$ , neither $(n = 2)$ ) differed markedly from previous sexual behaviour
204	(with women $(n = 8)$ , men $(n = 1)$ , both $(n = 25)$ , neither $(n = 0)$ ). Participants ranged in age from 22
205	to 41 years ( $M = 27.4$ years, SD = 4.74) and reported experience of between zero and six screens ( $M =$
206	2 screens; SD = 1.70), with the majority having previously attended ( $n = 26$ ). Age of first screen
207	ranged from 16 to 25 years of age ( $M = 20.4$ years, SD = 2.34), attributable to opportunistic screening
208	and the NHSCSP change in target age group from 20-64 to 25-64 in 2003. Of the 25 reporting test
209	results, nine had received abnormal or inconclusive results, of which two required treatment.
210	Participants were predominantly White British and educationally privileged.
211	
212	Participants commented on their own risk of cervical cancer, which were subsequently coded as: low
213	(n = 10), lower than average $(n = 3)$ ; average or 'normal' $(n = 8)$ ; higher than average $(n = 6)$ ; high
214	= 0); don't know ( $n = 6$ ); not answered ( $n = 1$ ). Of the six women reporting higher than average, two
215	cited existing gynaecological conditions, two cited familial (maternal) experience of cervical cancer,
216	and two cited multiple sexual partners and/or unprotected sex.
217	
218	Risk factors for cervical cancer were suggested by 27 participants, 17 of which included some
219	reference to sex. Risk factors were subsequently coded as: sexual activity (unspecified; $n = 5$ ); sex
220	with men $(n = 10)$ ; number of partners (male/ female unspecified; $n = 6$ ); age first had sex
221	(male/female unspecified; $n = 4$ ); sexually transmitted infections (STIs)/unprotected sex (male/female
222	unspecified; $n = 2$ ); genetics ( $n = 7$ ); smoking ( $n = 6$ ); lifestyle (including diet and exercise; $n = 6$ );

223	existing gynaecological conditions $(n = 2)$ ; hormone treatment $(n = 1)$ ; not attending for smears $(n = 1)$
224	1); age $(n = 1)$ ; and chance $(n = 1)$ .

#### 226 *Statistical Overview*

227 The 34 Q-sorts were entered into SPSS (version 13.0; manufacturer: SPSS Inc.), subjected to principal 228 components factor analysis and rotated to simple structure using Varimax. A five-factor structure 229 (accounting for 67.2% of the total variance) was selected as generating interpretable accounts 230 consistent with the open-ended comments and hearing 'many voices' (Stainton Rogers, 1995), 231 fundamental to Q-methodology. The decision was not limited to statistical significance; however 232 these factors were consistent with standard criteria of each factor presenting an Eigenvalue greater 233 than unity (EV> 1.00) and at least two factor exemplars (participants loading significantly and 234 exclusively onto the factor; Brown, 1980). Factor loadings of  $> \pm 0.33$  were statistically significant at 235 the 0.01 level;<sup>3</sup> however, this was increased to a more stringent level of> $\pm 0.49$ , maximizing the 236 number of factor exemplars (see Watts and Stenner, 2005: note 9) and corresponding open-ended 237 comments. The 27 resulting factor exemplars (Table 2) were weighted based on their factor loadings 238 (cf. Brown, 1980) to generate factor arrays (or composite sorts, Table 3), illustrating the Q-sorts of 239 hypothetical respondents with 100 percent loadings on the respective factors. 240 241 242 [Table 2 around here] 243 244 [Table 3 around here] 245 246 247 Factor Interpretation 248 Factor arrays were interpreted qualitatively based on positioning of items to explore conceptual 249 similarities and differences between accounts. This included identification of distinguishing 250 statements (Table 3) where a score on one factor differed from all the other factors by at least 3 251 (Brown, 1980). Open-ended comments provided by participants regarding sorting choices 252 supplemented the factor arrays. Factor scores denoting sorting positions are provided in parentheses 253 after the items (e.g. 16:+3). For illustrative purposes, open-ended comments are also provided in 254 parentheses, with 'p' and 'q' used respectively to denote the participant and item concerned. 255 256 Factor 1: Cervical screening is an essential health check that women have the right to refuse. 257 Eight participants' Q-sorts exemplified this factor. A defining feature of this account was the 258 perception of cervical screening as no different from any other health check (16:+3). This was 259 accompanied by a strong resistance to feeling judged about sexuality (32:-4), displaying a candid

- approach to sex with sexuality largely considered irrelevant to all aspects of cervical screening ('Sex
- is sex regardless of gender esp[ecially] if there is penetration', p17, q20). This appeared linked to
- wider understandings of health provision being devoid of moral meaning ('Maybe not disapprove as
- **263** [health professionals] are not there to judge', p16, q62) and rejecting any notion of cervical screening
- as female oppression ('If a male cancer could be diagnosed in a similar way they wouldn't have to do
- it. Ridiculous statement', p1, q8). Women who loaded onto this factor reported markedly different
- experiences of the procedure from exemplars on all other factors (items 6, 17, 57), consistent with
- comments illustrating the clinical nature of the procedure ('Disagree it's functional', p1, q6).
- 268

Importantly, although cervical screening was understood as a vital health check ('I think screening is essential!', p17, q3) offering a source of control (42:+2) and peace of mind (37:+4), it was felt that women must retain autonomy (12:-3; 'Though I believe [compulsory screening] would be of benefit to the health of the nation, I feel women must have the right to refuse', p2, q12). Empowerment was further suggested with this being the only factor where exemplars positioned attendance as their decision (43:-2), driven by their own health needs rather than external sources ('my doctor's

- disapproval is not what motivates me to have my smears!', p2, q62).
- 276

# 277 Factor 2: Cervical screening is a woman's health entitlement.

The Q-sorts of seven participants exemplified this factor. Factor 2 was most distinguished by its
stance against choice, being the only factor where the women who loaded onto it entertained
compulsory screening (12:+2) and felt more strongly than exemplars on any other factor that
attendance was 'Just something you have to do' (41:+4). This account also assigned the highest rank
to cervical screening as a right for all women (33:+6).

283

The NHSCSP was viewed positively as providing advice, encouragement and ensuring that women were not deprived of a health entitlement. This account appeared consistent with faith in the power of the medical system, with women wanting directive healthcare provision and appearing to desire emphasis on risk ('It's good they're strong about the cancer risk', p27, q39).

288

**289** Factor 2 shared with factor 1 alone an objection to cervical screening being viewed as a sexualized

- procedure (item 45). Interestingly, women who loaded onto factor 1 reported very different
- experiences, however, with the endorsement of items 6, 17 and 57 suggesting complexity of meaning
- beyond whether the procedure felt sexualized, or involved sexuality disclosure. Rather for factor 2,
- experience appeared linked to the health professional, with factor exemplars preferring a female
- screen taker more so than any other factor exemplars (47:+2) and offering several comments ('[Very]
- emotionally distressing if [the] doctor/ nurse doesn't have good manner and skill', p27, q9;
- 296 'Sometimes abrupt or too clinical', p6, q19). There appeared ambiguity about meanings of lesbian

- health clinics and the role of sexuality in healthcare access with some participants not wanting to
- disclose sexuality, possibly to avoid feeling judged ('I would never come out to [a] nurse or doctor',
- p29, q32) but reflecting that disclosure may improve the experience ('I feel that if not honest about
- sexual identity then feel uneasy about asking questions', p28, q10). This again highlighted differences
- between factors 1 and 2, with exemplars of the former perceiving and preferring a clinical
- 302 environment.
- 303
- **304** *Factor 3: Cervical screening is a vital test but degrading experience.*
- 305 Six participants' Q-sorts exemplified this factor. Here, distinguishing statements clearly contrasted
- with factor 1, with women instead perceiving cervical screening as markedly different from other
- health checks (16:-4) and questions too embarrassing to ask (10:+3), despite feeling unknowledgeable
- about the process (items 2, 7). Central to this account regarding the experience of the procedure, was
- its 'invasive', 'intrusive' and 'personal' nature in terms of emotional rather than physical
- 310 consequences (6:+4; 15:+4; 17:0; 57:+2). This was compounded by women feeling under scrutiny or
- 311 inspection (18:+2), judged about sexuality (32:+2; 'Definitely, because I wouldn't lie & say I'm
- straight', p18, q32) and the procedure viewed as potentially sexualized (45:+2). Perhaps
- unsurprisingly, this account was most in favour of lesbian health clinics (30:+2). While sexuality was
- 314 clearly central to meanings of the procedure, it did not appear associated with perceived risk of
- 315 cervical cancer or need for attendance.
- 316
- Factor 3 was thus characterized by women understanding cervical screening as a difficult, drawn-out
  and stressful decision-making process, balancing the experience with the need for attendance ('It's
  making a choice but also making yourself vulnerable difficult', p8, q42; '[Cervical screening gives
  peace of mind] once I have the result not going through the process itself', p14, q37; 'I do feel
  strongly that it is important but that it is awful', p22, q50).
- 322
- **323** *Factor 4: Cervical screening is a sensible thing to do.*

The Q-sorts of four participants exemplified this factor. The distinguishing statement for this factor appeared to suggest some doubt regarding the screening results (4:+2); however, women's comments instead indicated the possibility of error was seen as expected, simply warranting a repeat test ('I've heard of people who had abnormal results, had to have another done, but there was no problem', p11, q4).

329

- 330 This account was characterized by a degree of indifference towards cervical screening, further
- 331 suggested by both the nature and lack of open-ended comments. Cervical screening was understood as
- a holistic gynaecological check that could detect other health problems (55:+6). Unlike factors 1 and

- 333 3, women who loaded onto this factor were not concerned with risk of cervical cancer (27:-3; 'Don't
  334 even think about it', p10, q27) and did not view attendance as carrying meaning about risk (25:-4).
- 335

336 There was no suggestion of feeling coerced into attendance; however, there seemed no reason not to

- 337 go ('Never really thought about not doing it', p11, q40), being the only factor where screening was
- refuted as a hassle ('No it's only every 3 years!', p5, q31). Normative behaviour was also suggested
- by reactions to pain experienced during screening ('Yes but I've only had one maybe it was just a
- bad experience as it was the first time', p13, q17). Although experience was rated as more distressing
- than by exemplars of other factors (57:+3), women who loaded onto this factor did not elaborate.
- 342 Similarly, despite feeling the need to pluck up the courage (15:+4), this seemed minimized ('Yes but
- feel that it's just something everyone does', p5, q15). Sexuality did not appear linked to
- 344 understandings of risk (items 29, 35) or experience, with attending a lesbian sexual health clinic
- 345 viewed unnecessary (30:-3).
- 346

**347** *Factor 5: Cervical screening is an unnecessary imposition for some women.* 

- Two participants' Q-sorts exemplified this factor. Factor 5 was stable across possible factor structures,
  presenting numerous distinguishing statements. Unlike other factors, the characterizing statements
  (assigned extreme ranks) also distinguished the account. Positioned as an invasion of privacy (51:+6)
  the NHSCSP was a central feature, whereas all other factors shared consensus regarding the call–
  recall system (items 36, 39, 59).
- 353

Item 12 highlighted the opposing nature of accounts 2 and 5, presenting a distinguishing statement for
both. The two women who loaded onto factor 5 vehemently resisted suggestion of compulsory
screening (12:-6; 'No, no, no', p21, q12), emphasizing personal choice and control over one's body
(53:+5). Rather than entitlement being viewed a rights issue, there was suggestion of screening
comprising a form of female oppression (8:+2; 41:-2; 60:-2; 61:-4).

359

360 The other defining feature was the overt recognition of sexuality in the need for cervical screening. 361 Sexual activity was understood as presenting potential risk; however, heterosexual activity was 362 interpreted as presenting even greater risk. Exemplars reported feeling personally at low risk of 363 cervical cancer because of the nature of their sexual practices. Unlike other factors, screening was not 364 viewed as offering diagnosis of other health conditions (55:0), reinforcing that cervical screening was 365 not seen as relevant to the women who loaded onto this factor (44:+2). While acknowledging 366 controversy with such understandings, cervical screening was positioned as more important for 367 heterosexual women (29:+2; 'I can't quite believe I've put this where I have but yes I think so!', p21,

- **368** q29), for whom it was deemed valuable (54:+5).
- 369

# 371 Discussion

This study has highlighted the potential of Q-methodology in exploring diversity of meanings andunderstandings that SMW have about cervical screening, and the need to explore this diversity rather

than treating SMW as a homogenous group. Self-labelling of participants supported the use of the

- term SMW. Descriptive data regarding sexual identity and sexual behaviour were consistent with
- demands for sexual minority research to encompass both dimensions (e.g. Brogan et al., 2001).
- 377

With the exception of one account (factor 5 – screening as imposition), consensus existed in rejecting

379 cervical cancer and screening as more important for 'heterosexual' women. Accounts varied,

380 however, regarding whether the cancer risk presented a personal threat, and whether cervical

381 screening offered a way to tackle this risk, highlighting the need to consider both the understandings

- 382 of the procedure and target condition.
- 383

384 Although half of the women cited sexual risk factors for cervical cancer, only two identified STIs or 385 'unprotected sex'. No exemplars explicitly identified HPV, arguably reflecting its omission from 386 current information provision. For example, the nationally produced leaflet sent when women are 387 invited for screening as part of the NHSCSP (DOH, 2007) lists (hetero)sexual risk factors but omits 388 mention of HPV. Conflict over withholding of (hetero)sexual risk factors, including the role of HPV, 389 in cervical screening information provision has previously been considered through 'protectionist' and 390 'right to know' discourses (Braun and Gavey, 1999). The former is characterized by the belief that 391 such information may deter screening, for example through reinforcing links between promiscuity and 392 cervical cancer, despite it being in the interest of women to be screened. The latter emphasizes that 393 women are entitled to information that may affect them, with a view to making informed choices. 394 Accounts identified in the current study will now be considered within this framework.

395

396 A protectionist commitment prioritizes the biomedical emphasis of attendance as a desirable outcome, 397 such that 'The "best interests" of women as a group are prioritized over the potential interests of 398 individual women who may be in a position to use such information to reduce their risk of contracting 399 HPV' (Braun and Gavey, 1999: 1466). This could be interpreted as disciplinary power (Bunton et al., 400 1995) and a form of health fascism, prioritizing collectivism and identity as part of a group (i.e. 401 women) 'attempting to impose a certain lifestyle on us whether we want it or not' (Downie et al., 402 1996: 144). Non-attendance may therefore be interpreted using a deficit model, such that failure to 403 attend is seen as resulting from a lack of knowledge or concern about one's own health. Thus factor 5 404 (screening as imposition) may be interpreted through concepts such as 'unrealistic optimism'

405 (Weinstein, 1984), rather than considering whether risk perception may accurately reflect lowered

risk. Indeed discursive work has identified screening as constituting 'doing femininity', given its
association with feelings of normalcy (being a woman) and correctness (as a result of 'professional
discourse' of deviance surrounding non-attendance; Bush, 2000). However, these themes still remain
to be explored in SMW.

410

411 The protectionist stance is illustrated by several statements (items 40, 41, 60, 61) found to 412 differentiate factors 3 and 5 from the remaining factors. These two factors did not appear consistent 413 with the protectionist stance, albeit for different reasons. Women exemplifying factor 3 (degrading 414 experience) perceived cervical cancer as a salient health threat. However, the need for cervical 415 screening had to be weighed against their centrality of experience of the procedure, compounded by 416 issues surrounding sexuality. In contrast, factor 5 (screening as imposition) appeared more focused on 417 resistance to the NHSCSP because of disciplinary power and surveillance, compounded by perceived 418 irrelevance linked to sexuality. Such findings highlight the need to consider diversity when evaluating 419 acceptability as part of the national screening criteria, as well as the need to extend acceptability

420 beyond the test procedure to encompass wider meanings of the NHSCSP.

421

422 Although factors 1 (essential health check), 2 (health entitlement) and 4 (screening as sensible) 423 appeared consistent with the protectionist perspective, interpretation attending to sorting choices and 424 open-ended comments highlighted variation between factors. While factor 2 (health entitlement) was 425 compatible with a need for regulation, wanting directive healthcare, and factor 4 (screening as 426 sensible) seemed to position cervical screening as normative behaviour, minimizing any negative 427 aspects, factor 1 (essential health check) emphasized the need for personal choice and resisting social 428 obligation to comply. A right to know position may also be congruent with wider heath policy aims 429 relating to attendance, with health promoters hoping that informed choice will result in women 430 actively opting to have cervical screening and additionally engaging with primary prevention via 431 reduced HPV infection, thereby 'increas[ing] women's opportunity for making health-promoting 432 choices' (Braun and Gavey, 1999: 1472). This position is therefore subject to similar critical 433 reflections con- cerning rational choices being seen as synonymous with healthy choices (Marks et al., 434 2005). As well as compromising collective health, informed choice may be criticized for increasing 435 the stigma of promiscuity, and facilitating health citizenship, leading to victim-blaming for those who 436 develop the disease. Therefore, such a perspective similarly requires reflections on meanings of 437 attendance and careful consideration of how such information is communicated. 438

439 Informed choice has been advocated by the National Screening Committee (Gray, 2004) and appears

- 440 more consistent with addressing the criterion of acceptability to the population. Although informed
- 441 choice in cervical cancer screening has previously been discussed in relation to ethnic minority
- 442 women (Chiu, 2004), invisibility of SMW has continued in that literature. Therefore, employment of

- 443 an informed choice approach will be a fruitful framework to use in order to explore issues such as 444 HPV transmission between women and acknowledging diversity in sexual practices. But whether 445 women want informed choice is also an important question to explore. Consistent with factors 2 446 (health entitlement) and 4 (screening as sensible), a recent UK qualitative study (Jepson et al., 2007) 447 exploring informed choice with cancer screening (breast, cervical and colorectal) identified that 448 participants attending for cervical screening more commonly viewed attendance as a normative 449 behaviour than a choice and did not want to use information to make a choice. While factors 1 450 (essential health check) and 5 (screening as imposition) forcefully advocated the need for personal 451 choice, only women loading onto factor 1 in the current study felt that cervical screening was their 452 decision. Therefore, this issue of informed choice may warrant further consideration using 453 empowerment and/or decision-making models.
- 454

455 Future research into informed choice may benefit from a more holistic approach than information 456 provision by considering experience of the procedure, which was a prominent feature of several 457 accounts (factors 2, 3 and 4). In particular, as well as understanding the decision making as a source 458 of stress, women who loaded onto factor 3 (degrading experience) positioned the experience as 459 disempowering, possibly compounded by issues of sexuality. Indeed, future challenges 460 n developing anti-oppressive practice alongside informed choice were highlighted by several key 461 statements in the Q-set (items 13, 30, 32) and written comments emphasized the need for affirmation 462 of diversity ('It would be nice not to have my identity or ... sexual practices presumed', p3, q30; 'I 463 have been questioned about my sex life to the point where it was easier to say I'm a lesbian even 464 though I didn't want to', p30, q13). The current findings resonate with the US based research of 465 Johnson et al. (1981), published almost 30 years ago. It appears that British SMW's perceptions of 466 screening services and screening personnel are very similar despite both the intervening years and the 467 different settings in which these studies have been undertaken!

468

469 Suggestion of lesbian sexual health clinics (available in several UK cities) received a wide range of 470 responses ('Sign me up!', p30, q30; 'This is an awful suggestion. The lesbian community is 471 segregated enough', p31, q30; 'Not sure, prefer normal clinics – lesbian labels me', p6, q30). Some 472 participants felt that developing anti-oppressive practice within central provision would be preferable 473 ('[Lesbian clinics would tailor] questions more effectively and not pre-judge but equally all health 474 workers could be trained and more informed with regards to everyone's needs', p16, q30). Future 475 work may consider perceptions of such service provision and how to safeguard against contributing to 476 discrimination and heterocentric assumptions in non-specialized screening services. Issues discussed 477 here surrounding protectionist and right to know arguments warrant further investigation in light of 478 current developments in UK healthcare provision surrounding prevention of cervical cancer. For

479 example, media coverage following the proposed introduction of the HPV vaccine in the UK argued

- that it might encourage underage unprotected (hetero)sexual activity (see Davis, 2008). Such concerns
- 481 were also voiced in the US (Gibbs, 2006; Udesky, 2007) and in virtually every other country where
- the vaccine has been approved for use. It is also anticipated that HPV testing accompanying cervical
- 483 screening will be introduced into the NHSCSP within the next few years, with several pilot sites
- 484 already operational (Patnick, 2006). Critically, SMW and diversity of sexual identities, behaviours
- and practices remain invisible in discourse surrounding HPV, even where detailed discussions exist
- 486 surrounding the acceptability of the vaccine (e.g. Riedesel et al., 2005; Zimet, 2005).
- 487

Social constructionist approaches would envisage that these policy and practice developments impact
upon wider meanings of cervical screening and cervical cancer prevention. Indeed, the Ad Hoc Group
on Screening Research proposed an additional principle of continually reviewing screening
arrangements 'in the light of changes in demography, culture, health services, technologies, and the
epidemiology of the target conditions' (Downie et al., 1996: 144). However this has not been adopted

- **493** by the National Screening Committee (Gray, 2004).
- 494

# 495 *Study Limitations*

496 The Q-set was limited by omission of any items relating to HPV. This reflected an intention for 497 statements to be free from jargon and that the cultural analysis was conducted before HPV vaccine 498 proposals were announced in the UK. However, it would have been possible to include, for example, 499 reference to STIs. Additionally, only six of the 63 items explicitly mentioned sexuality (items 13, 20, 500 29, 30, 32, and 35). This may therefore have limited the potential for women to express salience of 501 sexuality relating to meanings, understandings and standpoints. Although not needing to be 502 representative, participant recruitment should facilitate diversity in order to access a greater 503 population of standpoints and meanings. This study appeared to achieve some diversity regarding 504 sexual identity and behaviour, particularly given the invisibility of bisexual women (Lee and 505 Crawford, 2007). However, diversity was likely limited by inherent challenges in sexual minority 506 research, for example, recruitment via community groups suggesting some public statement of sexual 507 identity. Importantly, the omission of heterosexual participants was not considered a limitation, 508 instead considering SMW without the need for comparison (Kitzinger, 2004). While caution must be 509 exercised in making a priori assumptions about demographics, the study was likely substantially 510 confounded by lack of racial, ethnic or socioeconomic diversity given the recruitment strategy 511 employed and this should be considered in future research in this area. 512

- 513 The study focused on the NHSCSP. However, information was not recorded on whether participants,
- although residing in the UK, had experienced this screening programme, or indeed one in another
- 515 country. Also, by deciding against restricting inclusion criteria based on screening history, there is a

need for caution in distinguishing neutral ratings, which could be attributable to women feeling unableto comment through inexperience of screening.

518

The aim of Q-methodology is not to be exhaustive, but to explore a general overview of accounts that
exist at a given point in time. It is not claimed that all possible accounts have been identified here.

- 521 Indeed, responses are not represented of the seven women who did not load significantly and
- 522 exclusively (five crossloaders and two non-loaders) onto one of the five factors. Another limitation
- 523 concerned the use of a fixed sort. Although common practice and considered more user-friendly than
- a full ranking (Brown, 1980), several participants reported feeling forced to position items on the
- 525 opposite side of 0, again suggesting the need for caution in interpreting the more neutral ranks. It may
- have been preferable, therefore, to employ 'free' distributions where the only requirement is at leastone item per rank position (Kline, 1994).
- 528

# 529 Conclusions

- 530 This exploratory study has recognized the need for affirmation of diversity within criteria for national 531 screening programmes. The accounts highlighted the complexity of meanings around cervical 532 screening, indicating that for screening to be more widely accepted it also needs to encompass wider 533 meanings of cervical screening, cervical cancer and the NHSCSP. Current demands by service users 534 for informed choice largely emphasize information provision, without attention to broader issues 535 surrounding empowerment and the experience of the procedure. There is also a need to reflect upon 536 wider values within health promotion, and to consider critical approaches to espousing informed 537 choice alongside the continued use of financial incentives within primary care (to ensure screening 538 occurs). Issues identified in this study are particularly pertinent given the prospective UK changes to 539 cervical cancer prevention around acknowledging the centrality of HPV. Continued invisibility of 540 SMW is evident within such developments, and warrants further attention.
- 541
- 542

# 543 Acknowledgements

544 We would like to thank all of the women who gave their time and shared their comments and545 experiences for this study.

- 546
- 547

# 548 Notes

<sup>1</sup> Health literature concerning the sexual orientation of women employs a diverse range of terms.

550 Rather than potentially implying behaviour (e.g. women who have sex with women), or self-identity

and community connections (e.g. lesbian or bisexual), the term SMW was adopted in recognition of

sexuality encompassing both sexual identity and sexual behaviour (Brogan et al., 2001) and to avoid

- alienating potential participants. Providing women the opportunity to also record their preferred terms
- aimed to safeguard against 'denying' or 'undermining ... self-labelling' (Young and Meyer, 2005).
- 555 The term SMW was additionally chosen to reflect the cultural minority status of this group (McNair,
- **556** 2003).
- 557 <sup>2</sup> It is possible to transform data from sorts that do not adhere to the quasi-normal distribution.
- 558 However it was deemed inappropriate to synthesize results from different procedures, particularly as
- several participants who did adhere to our instructions reported frustrations with the fixed sort and
- 560 may have generated different sorts using a free distribution.
- 561 <sup>3</sup> Statistically significant factor loadings are required to exceed 2.58 times the standard error of a zero-
- order factor loading, where the standard error is equal to  $1/\sqrt{n}$ , with n denoting the number in the Q-
- 563 set (McKeown and Thomas, 1988). In this instance,  $2.58 * (1/\sqrt{63}) = 0.33$ .
- 564 565
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- 667

669

670	Table 1	Quasi-normal	distribution
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671	
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noution	0	-5	-4	-3	-2	-1	0	+1	+2	+3	+4	+5	+6
position													
Number of	1	r	1	5	7	0	0	Q	7	5	1	2	1
items	1	2	4	5	1	0	9	0	7	5	4	2	1
items													

Participant	F1	F2	F3	F4	F5
23	.84*				
31	.70*				
1	.69*				
16	.64*				
33	.59*				
17	.52*				
12	.52*				
7	.51	.51			
2	.51*				
28		.67*			
4	.54	.60			
29		.59*			
27		.56*			
25		.55*			
24		.54*			
20		.53		.50	
9		.50*			
6		.50*			
18			.76*		
14			.67*		
22			.66*		
8			.65*		
30		.58	.58		
3			.55*		
26			.50*		
10				.69*	
13				.59*	
11				.56*	
5				.53*	
34					.87*
21					.77*
15	55				.57

674 Table 2 Rotated factor matrix: factor exemplars by factor

675

676 Note: Significant loadings are shown, with factor exemplars denoted by \*; values are reported to two

677 significant figures.

678 Table 3 Factor arrays: scores against each item by factor

679

Q-item	1	F1	F2	F3	F4	F5
1.	The biggest risk for cervical cancer is not having	+3	0	+3	-2	-4
	a screen.					
2.	I don't really know what an abnormal cervical	-2	0	+1	+1	-2
	screening result means.					
3.	Cervical screening is a waste of time and	-6	-6	-6	-5	-2
	resources.					
4.	The cervical screening results can't be trusted.	-2	-2	-1	+2	-1
5.	Cervical screening is more important for women	+2	-1	+3	+1	+1
	who have had sex at a younger age.					
6.	Having a cervical screen is an emotional	-1	+3	+4	+2	0
	experience.					
7.	I don't really understand the procedure.	-3	-1	0	-2	-2
8.	Men wouldn't be expected to do the equivalent.	-1	-2	-2	-1	+2
9.	Cervical screening could do more harm than	-5	-4	-2	-2	-5
	good.					
10.	It's too embarrassing to ask the doctor/nurse	-2	-1	+3	0	-3
	questions about cervical screening.					
11.	People who are close to me would want me to go	+5	+5	+5	+5	+2
	for a cervical screen.					
12.	Cervical screens should be compulsory.	-3	+2	-2	-1	-6
13.	Cervical screening involves disclosing my sexual	-1	-3	+1	+2	0
	identity to the doctor/nurse.					
14.	The procedure is not as bad as waiting for the	0	+1	-2	-2	-1
	results.					
15.	I have to pluck up the courage to have a cervical	0	+2	+4	+4	+1
	screen.					
16.	Cervical screens are no different to other health	+3	0	-4	0	0
	checks.					
17.	Having a cervical screen is a painful experience.	0	+2	0	+4	+3
18.	Having a cervical screen makes me feel under	0	0	+2	0	+1
	scrutiny or inspection.					
19.	The health professional could do more to put you	-1	+1	+1	+1	+3
	at ease.					

20.	Cervical screening is more important for	+2	0	-2	+1	+4
	promiscuous women, regardless of whether they					
	have casual sex with men or women.					
21.	Cervical screening is more important for women	+1	-1	-1	-1	+3
	who have had genital warts.					
22.	Using oral contraceptives lowers the need for a	0	-4	-2	-2	-4
	cervical screen.					
23.	There is a lot of pressure to have a cervical	+1	+1	0	0	+3
	screen.					
24.	If the test found something then it would already	-3	-2	-4	-3	-3
	be too late.					
25.	Having a screen would mean to me that I think I	+1	-5	-1	-4	+2
	am at risk of cervical cancer.					
26.	I am too private a person to have a cervical	-3	-2	-1	-4	0
	screen.					
27.	Cervical cancer is something I worry about.	+2	+1	+2	-3	-3
28.	Having had children lowers the need for a	-1	-2	-3	-1	-2
	cervical screen.					
29.	Cervical screening is something that only	-4	-4	-5	-4	+2
	heterosexual/"straight" women should worry					
	about.					
30.	Having a cervical screen would be less	-1	+1	+2	-3	-1
	embarrassing at a lesbian health clinic.					
31.	Cervical screening is a hassle.	+1	+2	+1	-1	+4
32.	The process makes me feel judged about my	-4	0	+2	-1	-1
	sexuality.					
33.	Cervical screening is a right for all women.	+4	+6	+5	+3	+1
34.	Cervical screening is for your own good.	+5	+5	+4	+5	+1
35.	Women who have never had sex with a man are	-4	-3	-3	-4	-1
	not at risk of cervical cancer.					
36.	The invitation system is a good way to make sure	+4	+4	+3	+3	-2
	all women are reminded.					
37.	Cervical screening gives me peace of mind.	+4	+3	+2	+2	0
38.	It is less important to go for a cervical screen if	-2	-5	-3	-6	-3
	you don't feel ill.					
39.	The letter to attend feels more like an order or	+1	-2	-1	+1	+4

	demand than an invitation.					
40.	Cervical screening is not something I question.	+3	+3	-1	+3	-3
41.	Cervical screening is just something you have to	+2	+4	+1	+2	-2
	do.					
42.	Having a cervical screen gives me control over	+2	0	0	+2	-1
	my body.					
43.	It feels like cervical screening is not really my	-2	0	0	0	0
	decision.					
44.	The procedure is not relevant to me and my life.	-5	-4	-4	-3	+2
45.	Cervical screening could be seen as a sexualised	-2	-3	+2	+1	+1
	procedure.					
46.	The information in the leaflet does not reflect the	0	+1	+1	0	-1
	experience.					
47.	It would bother me if the doctor/nurse was a	-3	+2	0	-1	+1
	man.					
48.	Cervical cancer is just down to chance.	+1	+1	-2	-2	0
49.	I know my body and don't need a cervical screen	-4	-3	-5	-5	+4
	to tell me something's wrong.					
50.	Cervical screening is not something I feel	+1	-1	-3	0	+1
	strongly about - I don't see what the big fuss is.					
51.	The cervical screening system feels like an	0	-2	-1	-1	+6
	invasion of my privacy.					
52.	Cervical screening is more important if you use	0	-1	-1	-2	-1
	tampons.					
53.	It's my body and having a cervical screen is not	-2	-1	-4	0	+5
	something I want to do.					
54.	Cervical screening can save lives.	+6	+4	+6	+4	+5
55.	Cervical screening could help find another	+4	+4	+4	+6	0
	medical problem.					
56.	Cervical screens should be done more	+2	+1	0	+0	-4
	frequently.					
57.	Having a cervical screen is a distressing	-1	+2	+2	+3	0
	experience.					
58.	Cervical screening is more important for younger	0	-1	0	+1	-5
	women.					
59.	The invitation system is a form of harassment.	-1	-3	-3	-3	+3

60.	It's irresponsible not to get a cervical screen	+3	+3	+1	+3	-2			
	done.								
61.	Cervical screening is just part of being a woman.	+3	+3	+1	+4	-4			
62.	My doctor would disapprove if I didn't go for a	+2	+2	+3	+2	+2			
	cervical screen.								
63.	Cervical screening is more important for smokers	+1	0	0	+1	+2			
	to worry about.								
Notes	Notes: Distinguishing statements are displayed in <i>italics</i> ; -6 denotes that participants disagreed most								

681 with the statement on weighted average.